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NATIONAL COMMISSION ON AIDS

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Report Number One:

Failure of
U.S. Health Care
System to Deal with
HIV Epidemic

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**NATIONAL COMMISSION ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME**

1730 K Street, N.W., Suite 815
Washington, D.C. 20006
(202) 254-5125 [FAX] 254-3060

December 5, 1989

President George Bush
The White House
Washington, DC 20500

Dear President Bush:

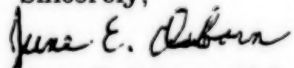
The official charter for the National Commission on Acquired Immune Deficiency Syndrome (AIDS) was signed on August 2, 1989. Since that time the National Commission has convened a series of hearings to solicit information and recommendations from experts in the field of medicine and public health policy to assist the Commission in meeting its statutory mandate of "promoting the development of a national consensus on policy concerning acquired immune deficiency syndrome."

The testimony we recently heard on health care and financing was so compelling we felt it is vital to write to you now, rather than wait until our statutorily required annual report next August. In fact, the Commission will continue to bring these urgent matters to your attention and to the attention of Congress as we hear from the experts about the Human Immunodeficiency Virus (HIV) epidemic and what is needed to respond to it.

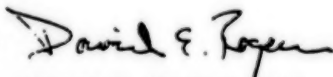
The following represents the first of such reports which we hope will prompt appropriate action.

On behalf of all of the members of the National Commission on AIDS, we look forward to being able to continue to bring important information to your attention.

Sincerely,



June E. Osborn, M.D.
Chairman



David E. Rogers, M.D.
Vice Chairman

cc: The Honorable Robert C. Byrd
President Pro Tempore of the Senate

The Honorable George J. Mitchell
Majority Leader of the Senate

The Honorable Bob Dole
Minority Leader of the Senate

The Honorable Thomas S. Foley
Speaker of the House of
Representatives

The Honorable Richard A. Gephardt
Majority Leader of the House of
Representatives

The Honorable Robert H. Michel
Minority Leader of the House of
Representatives

NATIONAL COMMISSION ON AIDS

Report Number One

OVERVIEW

"We don't have time to sit around and have this Commission live out its life and issue another report and have another report, another Commission. . . . We have to act and we have to act swiftly."

This testimony was presented before the National Commission on Acquired Immune Deficiency Syndrome at a hearing held in Washington, D.C., November 2nd and 3rd of this year. The Commission convened a meeting of experts to examine the global, national and local challenges confronting the United States in the HIV epidemic. The message was clear and alarming:

- There is a dangerous, perhaps even growing, complacency in our country toward an epidemic that many people want to believe is over.
- Far from over, the epidemic is reaching crisis proportions among the young, the poor, women and many minority communities. In fact, the 1990's will be much worse than the 1980's.
- The link between drug use and HIV infection must be acknowledged and addressed in any national drug strategy.

- There is no national plan for helping an already faltering health care system deal with the impact of the HIV epidemic.

Over the coming months, the Commission intends to bring the message of experts who have studied the problems and proposed the solutions to those who have the power to act. The Commission believes it is time to match rhetoric with action.

This letter is intended to outline the first of these messages from experts in the field of health care and financing: the public health care system in this country is not working well and nowhere is that more evident than for people with HIV infection and AIDS. While AIDS is not the cause of the health care system's disarray, it may well be the crisis that could pressure responsible national action to correct its serious shortfalls.

■ SCOPE OF THE PROBLEM

To date, AIDS has claimed more American lives than the Vietnam War. Over the course of the next four years in this country, AIDS will likely claim an additional 200,000 lives. It is estimated that by 1991 AIDS will be among the top ten leading causes of death in the United States. Nearly one-half of all AIDS cases reported to the Centers for Disease Control (CDC) through May 1989 were diagnosed in people 30 to 39 years old. By 1991, ten years after the first AIDS cases were reported, AIDS will far exceed all other causes of death for people between the ages of 25 and 44 years. In testimony before the Commission, it was stated that nine times more adults around the world may develop AIDS during the 1990's than have developed AIDS during the 1980's.

The proportion of AIDS cases with intravenous drug use as a risk behavior has risen from 25 percent prior to 1985, to 30 percent in 1988. In New York City, alone, an estimated 100,000 intravenous drug users are HIV-infected.

The HIV epidemic is not just a New York City or a San Francisco problem as some would

like to believe. While it is true that before 1985, 44 percent of all cases of AIDS were diagnosed in the New York City or San Francisco areas, by 1988 this proportion had fallen to 25 percent. By 1991, it is expected that 80 percent of new AIDS cases will come from outside New York City and San Francisco.

In increasing numbers, these new cases will be women and children. As one prominent pediatrician from New Jersey told the Commission, "As a society, we claim to protect and cherish our children, but in fact, we have placed women and children squarely in front of an on-rushing HIV epidemic."

The cumulative incidence of AIDS cases is disproportionately higher in Blacks and Hispanics than in whites. Fully 25 percent of all persons with AIDS in the United States are African-American and the number is growing. In fact, there has been, as one witness told the Commission, "a disproportionate impact of HIV on disenfranchised populations, gays, the poor, racial minorities, women, adolescents and drug users--populations having already less than optimal access to quality health care.... The development of a national care and treatment strategy will require a rethinking of our past effort."

■ ACCESS TO CARE

Recent years have seen considerable advances in the development of new HIV-related drugs, including the prospect of treating HIV infection before symptoms develop. But scientific breakthroughs mean little unless the health care system can incorporate them and make them accessible to people in need.

The belief that Medicaid will pay for the health care needs of the growing number of low income people with HIV infection and AIDS is, as one expert witness told the Commission, a "Medicaid fantasy." According to a 1987 U.S. Hospital AIDS Survey, almost one quarter of all AIDS patients have no form of insurance, private or public. Less than 20 percent of the persons with AIDS treated in southern hospitals were

covered by Medicaid, compared with 55 percent in the Northeast and 44 percent nationwide.

For the medically disenfranchised, there is no access to a system of care. For those who have no doctor, no clinic, no means of payment, access to health care services is most often through the emergency room door of one of the few hospitals in the community that treats people with HIV infection and AIDS. Five percent of the nation's hospitals treat fifty percent of the people with AIDS.

For those who are covered by Medicaid, access to care is better than for those who have no insurance at all. However, the obstacles to care under Medicaid funding can be insurmountable for many. One obstacle is the wide variation among states in Medicaid eligibility and scope of benefits. The Food and Drug Administration (FDA), under considerable public pressure, has struggled with mechanisms to speed new drugs to the market. Yet there is no requirement that Medicaid make even life-prolonging drugs such as zidovudine (AZT) available.

Another obstacle to needed care for persons with HIV infection and AIDS who qualify for Medicaid is the low reimbursement rates. Stunning examples of Medicaid physician compensation rates far below those by private insurance or Medicare were illustrated during the Commission hearing. For example, a new patient intermediate office visit in New York City is compensated by Blue Cross at \$78, by Medicare at \$80, and by Medicaid at \$7. One witness indicated that physicians in New York with large AIDS practices were reluctant to refer Medicaid patients for specialty consultations because of low levels of reimbursement--levels so low that several physicians said the few dollars at stake per office visit were not worth the time and paperwork to bill the Medicaid program.

In summary, a series of problems have resulted in a health care system singularly unresponsive to the needs of HIV infected people: the initial appearance of HIV infection and AIDS in groups often shunned by the larger society--gay men, the poor, minorities, and intravenous drug users encouraged a slow response, a gross

lack of training support for primary care physicians to treat people with HIV infection and AIDS, and serious disincentives for physicians to take Medicaid patients and perhaps poor people in general.

■ WHAT IS NEEDED?

First, frank recognition that a crisis situation exists in many cities that will require extraordinary measures to overcome. Significant changes must be made not only in our health care system but in how we think about the system and the people it is designed to serve. As one witness told the Commission, it can no longer be "business as usual."

Second, the creation of a flexible, patient-oriented, comprehensive system of care, closely linking hospital, ambulatory, residential, and home care. Primary care physicians must be central to such a system. But if primary care doctors are to care for patients with HIV infection and AIDS, they need the financial, social and institutional support to assist them in managing complicated patients.

Third, consideration of the creation of regional centers or networks of care, perhaps using the already existing regionalized hemophilia treatment program as a model. These centers would not serve as a replacement for the care provided by primary care physicians but would provide backup and consultation to help strengthen community based primary care.

It is essential that everyone be afforded early intervention and access to care. In addition, the availability of backup and consultation from appropriate specialists is required to provide the assistance and encouragement primary care doctors need to see more people with HIV infection and AIDS. Regional centers should also provide the appropriate link with the hospital when hospital services are needed.

Fourth, create units which can treat patients who have both HIV infection and drug addiction. The availability of drug treatment on request is essential for responding to the combined HIV and drug epidemic that imperils not

only drug users but also their sexual partners and children.

Given the massive link between drug use and HIV infection, and the fact that there is an alarming increase in the number of new infections among intravenous drug users, the Commission wishes to go on record in expressing its surprise and disappointment that the White House National Drug Control Strategy mentions AIDS only four times in its ninety pages of text and not at all in its recommendations or discussions of how to allocate resources. The President's drug strategy simply must acknowledge and include HIV infection and AIDS.

Fifth, provide comprehensive health care services under one roof. Fragmented services create additional barriers to needed health care. Often mothers will seek health care services needed for their babies but are not able to then gain access to care for themselves. Health care services for women and children need to be provided in one place. For the homeless, housing and health care need to go hand-in-hand. This is true not only for those who are homeless today but for those who will become homeless tomorrow because of the HIV epidemic.

■ WHAT WILL IT COST?

Estimates of the national costs of direct medical care for persons with AIDS in 1991 range from \$2.5 to 15.1 billion (in 1988 dollars). These estimates represent a small fraction of the total health care costs for the nation - from less than one to slightly more than three percent. We simply must be prepared to make these expenditures.

■ WHO IS RESPONSIBLE FOR ACTION?

In carrying out its mandate, the National Commission on AIDS will attempt to delineate clearly the roles and responsibilities of various levels of government and the private sector in responding to and managing the HIV epidemic.

To date, there is no national policy or plan, and no national voice. Currently, as one witness testified, without the definition of roles each level of government points a finger at another and says it is their job. Clearly, managing the HIV epidemic is a responsibility which must be shared by all.

Without federal leadership the states have assumed various degrees of responsibility for planning, coordination and the provision of care. Likewise some local governments have played key roles in determining how patient services could be provided and in demonstrating important models for service delivery.

The role of the private sector voluntary and professional AIDS service organizations has been all important in managing the HIV epidemic to date. Foundations and corporations have also been important and their roles need better recognition and definition.

"We must," the Commission was told, "move swiftly to bring the missing players to the table...this includes a greater presence of our federal, state and local governments in terms of leadership, financing and service delivery. It includes the support and cooperation of the insurance industry, employers, physicians and other medical providers, and last but not least, the pharmaceutical industry as well."

Responding to the challenge to bring the "missing players to the table," the National Commission on AIDS intends to do just that in hearings, working groups and other forums that can swiftly translate the facts into action and hold us all accountable for the national strategy that is long overdue. The time has come to define exactly what needs to be done, and measure how far we have come, and how much farther we still have to go.

END

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